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Which is the Editorial for the *E-Health Special Issue* of the Australian Journal of Primary Health, published 18 November 2013.

"The Rhetoric and Reality of E-health: A critical assessment of the benefits of e-health in primary health care"

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We are delighted to have been invited to guest edit this special issue of the Australian Journal of Primary Health and to bring you 13 papers looking at aspects of The Rhetoric and Reality of E-Health in relation to primary health. We were pleased to see the enthusiastic reaction from authors to the Call for Papers and have thoroughly enjoyed reading the submitted papers and guiding them through the reviewing and revision processes.

In developing the special issue, a number of things have been foremost in our mind. Firstly, what exactly is e-health, and is it different from telehealth, ICT for health, online health and other terms? The WHO defines e-health as the use of information and communication technologies for health, with e-health innovations including electronic health records, computer-assisted prescription systems and clinical databases, ICT-supported clinical care, online health information for the general public and scientific information for professionals, platforms for publishing and disseminating health alerts and supporting administrative functions (WHO 2006). The papers in this special issue reflect a wide understanding of e-health and cover topics including health professional training to use online health systems, issues around access and equity for consumers, and electronic records and management. The papers cover areas such as maternity care, dentistry, general practice, mental health, cancer care, chronic disease, nursing, and community health. Secondly, we were keen to develop this special issue in light of the techno-optimism which we feel prevails within some parts of

government and of the health professions in Australia in relation to e-health, and which is not always balanced by a critical perspective of who actually benefits, or of unintended consequences of its introduction or expansion.

Australia's national E-health Strategy (AHMAC 2008) envisages 'a safer and more sustainable health system that is equipped to respond to emerging health sector cost and demand pressures', and it sees this being achieved by changing the way information is accessed and shared across the health system. This means that interactions with the health system by consumers, care providers and health care managers will be increasingly through electronic means. In particular, the Strategy notes the 'potentially important role e-health may play in delivering Australians a higher quality, safer, more equitable and more efficient health system' and that 'e-health should be considered a means to potentially address the ever-increasing costs of Australian health care' (AHMAC, 2008: 23).

Australia's national E-Health Strategy has substantial goals, including that by 2018 (ie in just 5 years from now) up to 20% of consultations will be by electronic consultation or telehealth capability, and over 90% of care providers will be using standards compliant systems for patient, clinical and practice management that support e-health priority solutions such as the electronic transfer of prescriptions, test orders/results, referrals and event summaries. It also envisions that by 2018, 50% of consumers will be actively accessing and using a personal Electronic Health Record to manage their health and interact with the health system. The Strategy sees 'latent capacity in the system represented by consumers themselves playing a more active role in the protection and management of their personal health outcomes' (AHMAC 2008: 1) although it does not detail how all consumers will be up-skilled and resourced to be able to this.

Similarly, Australia's E-Mental Health Strategy (Department of Health & Ageing 2012) focuses on mainstreaming the provision of online health information and online support services for consumers and carers, seeing these as widely accessible (but with little acknowledgement of the inequities in technical Internet access by geography and socioeconomic status across Australia, or of how social/cultural and educational barriers to successful Internet use can be overcome to provide e-mental health which is truly accessible by all). The Strategy also outlines the need for training of the mental health workforce to provide services in these ways.

The National E-health Strategy sees the approach as threefold:

(1) **to improve the quality and safety** of the Australian health system (and thereby reduce avoidable demand for health care services) through improved data and monitoring, access to decision support tools for care providers and up to date consumer information and knowledge sources at the point of care; access to better quality datasets of treatment effectiveness; automatic monitoring of individual care; and access to timely and comprehensive data for more effective health surveillance and management.

(2) **to improve system accessibility, equity, processing and cost efficiency**, by allowing care providers to readily know who and where other providers are, to facilitate referrals and timely access to care, to supporting managers with access to quality data sources to inform service and workforce planning, by reducing the time consumers and care providers spend manually booking appointments, ordering treatments, and repeating and sharing information across the health sector, and by reducing the time and cost spent undertaking unnecessary or duplicated treatment activities such as diagnostic tests; reducing the amount of required travel to / from rural and remote communities; and enabling health care managers to more effectively identify and address system inefficiencies.

and (3) **by empowering consumers to better manage their own health**, for example through providing better visibility of the location of care providers, the services offered and their availability; and by providing rural, remote and disadvantaged communities with better access to a range of health care services through the use of technologies such as telehealth.

These approaches are reflected on the ground for example in the Commonwealth's national e-health record system (formerly known as the Person Controlled Electronic Health record - PCEHR), whose creation was recommended in the 2008 National E-Health Strategy and supported by the 2009 National Health and Hospitals Reform Commission. Electronic communication and sharing of clinical information by health professionals about patients requires the information first to be collected and processed in an electronic form, and secondly for systems to be in place to enable and facilitate the communication of that information between the health professionals who are caring for a person. General practices in Australia are heavily, if not fully, computerised, with some already communicating electronically in both directions with other health professionals and organisations. However, many other primary care health professionals still make their clinical records on paper and use electronic systems only for administrative functions. This precludes them and their patients from receiving opportunistic reminders, warnings, alerts and educational information during consultations or other service delivery, and from being able to conduct automated audits of their

care, all of which have been shown to be effective (see for example: Dexheimer et al 2008; Frank, Litt & Beilby 2004; Garg et al 2005; Kawamoto et al 2005). A vast array of educational materials and peer support is also available electronically for health professionals, but some may be struggling to learn how to use these resources. Aggregating clinical data from multiple health professional practices and organisations and analysing them then has the potential to provide new understandings of patterns of health, illness and use of health services. And thirdly, the Internet now supplies health information and information about health services for people with health issues, needs or problems, and their relatives and carers, if they have the means and resources to access and use the Internet.

However, not all decision-makers are convinced that e-health can reduce costs, improve service quality or enable equity in healthcare access (WHO 2012). Furthermore, governments can be ambivalent as evidenced by the recent reduction in the number of video consultations resulting from government changes to funding for these services (Wade 2013). In considering the expansion of ICT use within the health system, we agree it is important to resist the 'magical thinking' that installation of electronic clinical and administrative systems can by itself transform the health care system and compensate for its structural problems (including Australia's Federal-State funding divide or the lack of any requirement for citizens to belong to only one general practice at a time) and we need to address difficult challenges such as how to motivate ICT adoption among care providers, consumers and carers to achieve better health and health care (Diamond & Shirkey 2008). Our own work and that of others has shown that Australians from lower income and disadvantaged backgrounds face challenges to using ICT in general, as well as for health purposes, and may need intensive support if they are to become the 'empowered consumers' envisioned by the E-Health Strategy (eg Newman et al 2010; Baum et al 2012; Goodall et al 2010; Raghavendra et al 2013; Wen et al 2011). Some studies of the effectiveness of e-health also show that benefits do not necessarily accrue as expected. For example Narring et al's (2013) RCT study in Switzerland found that texting appointment reminders to mobile phones for young people did not increase clinic attendance rates. Lupton (2013) argues that despite an increased focus on broader social determinants of health (as evidenced in Australia's recent Senate Inquiry: Commonwealth of Australia 2013), the increased use of ICTs in health is promoting a renewed focus on individual health risk as well as personal responsibility for health, which may further entrench socioeconomic disadvantage and reduce health care access. Nevertheless, innovative approaches that use sophisticated automated analysis of clinical information to generate consumer-oriented education and advice may help to improve equity of care. Patients welcomed a unique intervention that we developed that automatically generated targeted education, information and advice about preventive activities for people who

were about to see their GP. The patient and the GP could immediately discuss that information, and patients reported acting on the advice (Frank, Stocks & Aylward 2011).

For this special issue we therefore aimed to encourage papers which take a critical perspective, as well as those which provide some degree of evaluation of e-health initiatives. We asked authors to consider issues relating to equity of access, workforce issues, management systems to improve care provision, and in particular to consider who e-health does work for and in what context, who it works less well for and what can be done to address this, and what are the practical challenges of implementing and sustaining e-health initiatives in primary care. The 13 papers in this special issue cover themes which broadly relate to the three "E-health Solution Categories" of the National E-health Strategy: (1) **Service Delivery** eg chronic disease management solutions; telehealth and electronic consultations; (2) **Electronic Information Sharing** - specifically the training of health professionals to be able to do this; and (3) **Online Information Sources** - access and equity in relation to consumer use of health information websites, and evaluation of the effectiveness of such websites, electronic health records, and data use for management.

Firstly we have three papers focussing on Service Delivery. The paper by Scott and Beatty entitled ***Feasibility study of a self-guided CBT internet intervention for cancer carers*** shows that online support may be useful for people caring for their relatives who have cancer, and also discusses the difficulties that can be faced when recruiting for such studies. The paper by Dowell et al builds on previous work in examining how the use of electronic clinical systems changes the interactions between patient and doctor in the consultation. And finally, Raven's paper on ***Video-based telehealth in Australian primary care: current use and future potential*** provides some examples of how video consultations are not only facilitating access to care, but also enabling the simultaneous provision of care by primary and secondary care health professionals, creating a new model of care that may reduce or abolish the existing boundaries between them.

Next come four papers about Electronic Information Sharing between professionals and organisations, and the need for professionals to upskill their e-learning as well as being able to train online. Firstly, Heartfield et al's paper ***e-Learning competency for practice nurses: an evaluation report*** finds that practice nurses who used an online education program to learn about their role in a new coordinated care scheme appreciated the convenience and self-paced nature of online education, but were limited by inadequate hardware and software in some general practices, and by their own low level of computer literacy. Similarly, Barnett's paper looks at ***Usefulness of a virtual community of practice and Web 2.0 tools for GP training: experiences and expectations of GP***

registrars and supervisors. It shows that a small group of GP registrars, who were high users of the Internet and who were posted to rural areas for part of their training, believe that being able to discuss clinical and other topics online and to learn from each other could reduce their professional and social isolation. The paper by Walker et al on ***Learning from the implementation of inter-organisational web-based care planning and coordination*** describes some of the barriers to this resulting from the differing roles and structures of organisations that are trying to work together, and by the lack of interoperability of their electronic systems. Lam et al's paper looks at the role of e-health as a way of bringing together useful datasets from across many private dental practices for researchers in ***A critical discussion of the benefits of e-health in population-level dental research.***

We then have a large number of papers looking at various aspects of Information Sources online. Two papers, by Rodger et al and Hearn et al, take a critical look at the extent to which online health information is useful to women during pregnancy and early motherhood: ***Pregnant women's use of information and communications technologies to access pregnancy-related health information in South Australia*** and ***Online healthy lifestyle support in the perinatal period: What do women want and do they use it?*** The paper by Tieman and Bradley then reminds us of the need to evaluate how effective e-health initiatives are in reality, rather than assuming that they are effective merely because they exist. They provide us with a ***Systematic review of the types of methods and approaches used to assess the effectiveness of healthcare information websites.*** This links on nicely to the paper by Patel and Osborne on ***Evaluation of a website which promotes social connectedness: lessons for equitable e-health promotion.*** This paper shows that online resources may inadvertently lead to further advantage for those who are already advantaged, rather than leading to improvements for the disadvantaged. This is an aspect of e-health which we must clearly bear in mind as we design and implement initiatives. Similarly, Keane et al's paper on ***E-mental health in South Australia: impact of age, gender and region of residence*** concludes that although the anonymity and convenience of the Internet hold great potential for providing information to the population about depression, anxiety or relationship problems, in fact use is shaped strongly by gender, age and whether people are living in rural or urban settings. Finally, the paper by van Dooren et al is on ***Improving access to electronic health records for people with intellectual disability: a qualitative study.*** This paper highlights the ways in which particular groups need special understanding and accommodation if they are to be involved in national e-health initiatives.

The papers published in this issue of the Journal describe a range of studies and projects that explored issues for different kinds of people accessing health information online. Making access to e-health equitable, and evaluating the utility of online resources for different kinds of people are

important aspects of a national e-health system, but may be neglected in the focus on technical developments. The papers remind us that e-health needs to work not just for people who can manage their own health care, but also for those who need a little or a lot of help from others to access and benefit from online health information and communication and from a national e-health system. Interestingly, van Dooren et al's exploration of the experience of people with intellectual disabilities is the only paper that addresses any aspect of the Commonwealth's national e-health record system (formerly the PCEHR). A major share of the National eHealth Transition Authority's public funding that approaches \$1,000,000,000 has been invested in the development and implementation of the national e-health record system. The national e-health system has been the subject of much rhetoric, but what is the reality of this very expensive project? The 'scorecard' recently published by the National eHealth Transition Authority (NEHTA 2013) provides some statistics about elements such as the number of e-health records that have been created, but it is difficult to assess from these statistics what 'meaningful use' of the system has been made so far.

Who is in charge of e-health developments in Australia? The still-current 2008 National e-Health Strategy 'provides a useful guide to next steps for Australia in its E-Health journey'. One of the Strategy's recommendations is to: 'Establish(ing) an E-Health governance regime to enable effective coordination and oversight of national E-Health activities', because 'given the strong national consensus for action and the amount of E-Health activity occurring at a national, State and Territory, regional and local level around the country, there is the need to move quickly to establish an appropriate long term E-Health governance regime'. However, the role and funding of the National eHealth Transition Authority have been reduced, development and operation of the national e-health record system has been taken over by the Commonwealth Department of Health and Ageing, and the cooperation of State health departments with the Commonwealth is variable. Little or no progress seems to have been made towards establishing the recommended e-health governance regime. We also lack a national repository for exchange of information and knowledge about e-health, in which the learnings from the many different studies and projects related to e-health, such as those described in the papers in this issue, can easily be accessed, shared and discussed. The database of research activities and of knowledge that is maintained by the Primary Health Care Research and Information Service (PHCRIS) may be the nearest equivalent that we have currently to such a national repository.

Increased access to health care via telehealth, including video consultations, has been a proposed major benefit of the National Broadband Network (NBN). Its structure was fiercely debated by the parties before the recent federal election that resulted in a change of government. It remains to be

seen whether e-health developments will now continue along the same path or go in new directions. It is not yet clear whether the new government's plans to implement the NBN will impact on current or future e-health initiatives or will change their level of quality, speed or timeliness, the different types of personal and professional users, costs of implementation and costs of upgrading, out of pocket costs to users, and future changes in broadband technology. It is also not yet clear whether there will be any impacts on the ability of Australians with poorer health, lower income and those living in rural areas to benefit from future advances in e-health. Nevertheless, most urban and rural areas already have sufficient bandwidth to conduct video consultations and those that do not have this could be prioritised for the new satellite service that had been proposed by both major parties. As some of the papers in this issue of the Journal demonstrate, the availability of telehealth is changing and will continue to change models of care. Wider implementation of telehealth services will need to be supported by appropriate changes to the organisation and funding of the health system.

What are the policy messages from the papers published in this issue of the Journal? One of them is that developing and evaluating one relatively small function at a time may be more successful than developing complex or massive systems that may not address the needs of the people that the health system is serving or should be serving, or the needs of health professionals. Another message is that a lack of technical and other standards continues to inhibit the automated transfer and sharing of information between health professionals and organisations. A third message is that the current system of funding of general practice, which supports only some limited forms of interaction between GPs and their patients, is inhibiting innovation in the provision of care, particularly in telehealth.

We take this opportunity to thank all the authors for submitting their work to this special issue which highlights both benefits and challenges of e-health and ICT use to improve Australia's health system and health outcomes. We are also very grateful for the time and effort contributed by the reviewers in helping to ensure the quality of the final articles. We thank the journal's Editor-in-Chief Professor Libby Kalucy for encouraging us to take on the task of conceptualising and guest editing this issue, and we were well supported by CSIRO publishing's Leanne Hamilton and Jenny Macmillan. We also thank Dr Tori Wade for spending time with us to discuss telehealth and the NBN.

We hope that this issue will stimulate discussion, and encourage further research that examines the use of existing and new electronic clinical and administrative systems in primary health care, and the ways in which consumers can be supported to encourage their involvement. We hope that

researchers, practitioners and policymakers will consider the benefits of these systems and their use, and also the new issues that they may raise for the safe and efficient provision of high quality primary health care. Whilst the papers in this issue show that primary health care is demonstrating innovation and imagination in relation to e-health, we encourage all involved to continue to take a critical perspective of the rhetoric and reality of e-health. We need to identify ways in which all Australians, and different groups of Australians, can really benefit from the potential which e-health offers in terms of improving service quality, reducing costs, and enabling equity in healthcare access and health outcomes.

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